RESEARCH ARTICLE

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Health Seeking Behaviour among Cancer Patients with the aid of Geographic Information System: A Mixed-Methods Study from Western India

Garima Singh[1], Pankaja Raghav[2]*, Neeti Rustagi[3]

Abstract

Background and Objective: Cancer prognosis depends on early diagnosis and treatment and awareness, beliefs, accessibility, and affordability of health services. Delays in patients seeking health care increase mortality risk. This study has been undertaken in rural Jodhpur (Rajasthan, Western India) to determine the health-seeking behaviour related to common cancers and the factors affecting them. **Methodology:** A community-based mixed-methods study was conducted in randomly chosen one-third of the Mandore block of Jodhpur villages. Data was collected from individuals diagnosed with cancer/their relatives. In-depth interviews (IDI) were conducted with the frontline workers, cancer survivors, and their caregivers. A geographic information system (GIS) was also used to depict healthcare facilities accessed by cancer patients. **Results:** A total of 146 participants (diagnosed with cancer) were included in the study. About one-third (34.2%) preferred alternative medicine along with allopathic medicine. The behaviour of changing hospitals frequently was depicted mostly by patients suffering from primary brain tumours (62.5%). Forty-five (31%) participants did not continue their treatment after initiation. From the content analysis of IDI, major factors for delays in health-seeking were misconceptions, superstitions, stigmatisation, financial burden, miscommunication from doctors, no proper referral mechanism, and unfelt need to visit healthcare. None of the participants were aware of the screening services provided and the benefits of screening services. Availability of initial treatment at peripheral centres and training activities for frontline workers and teachers were the major recommendations to improve cancer prevention and control. **Conclusions:** Alternative medicine usage was common among cancer patients. Leaving treatment in between was also observed among one-third of the participants. Misconceptions, superstitions, stigmatisation, and financial burden were major factors enlisted for health-seeking delays.

Keywords: Cancer- GIS in health- cancer survivors- patient acceptance of healthcare- health-seeking behaviour

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Introduction

Approximately 20 million new cancer cases and 9.7 million cancer-related deaths are reported annually, with lung cancer being the leading cause of death, followed by breast and colorectal cancers, and a projected 77% increase in new cancer cases by 2050, reaching 35 million globally [1]. India ranked third after China and the United States of America. It was predicted that cancer cases in India would increase to 2.08 million, accounting for a rise of 57.5 per cent in 2040 from 2020 [2].

Health-seeking behaviour is defined as an individual's deeds to promote maximum well-being, recovery, and rehabilitation; this could happen with or without health concerns and within a range of potential to real health concerns [3]. Health behaviour plays a significant role in cancer development, detection, and course. Relevant health behaviour includes prompt medical care-seeking and cessation of smoking and drinking after diagnosis. There are limited studies globally and in India which focus on the health-seeking behaviour of cancer patients [4]. As mentioned by Powe D B et al. [5] in their study, Cancer fatalism is the belief that death is inevitable when cancer is present and has been identified as a barrier to participation in cancer screening, detection, and treatment.

There are several gaps in the evidence base around non-communicable diseases, especially cancer, that need further investigation [7]. In lower-middle-income countries like India, patients with cancer generally have a poor prognosis compared to patients in high-income countries. The probable reasons are lack of awareness, late diagnosis, and inequitable access to affordable curative services [6]. About 70% of the population lives in rural India. However, 95% of cancer care facilities are in urban

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*[1]Department of Community Medicine, Heritage Institute of Medical Sciences, Varanasi, India. [2]Department of Community Medicine, All India Institute of Medical Sciences, Jodhpur, India. [3]Department of Community Medicine and Family Medicine, AIIMS Jodhpur, India. *For Correspondence: drpankajaraghav@gmail.com*

India [7]. In rural India, PHCs do not have the facility for diagnosis and treatment which is limited to tertiary care hospitals and regional cancer centers.

Cost of treatment is another major issue in cancer therapy leading to delayed presentation of cancer in developing countries like India where two-thirds of the population lives in rural areas. Relating the symptoms of cancer to mild ailments, lack of awareness, illiteracy, financial constraints as well as myths and superstitions lead to delays in health-seeking [8]. Most of the screening tests are available at higher centres only. Therefore, at the time of the first contact with the healthcare provider, the disease has already spread to regional tissue or metastasis has occurred in most of the cancer patients [9].

Studies are needed to find out the causes and factors affecting health-seeking behaviour among cancer cases. Hence this study has been undertaken to determine the factors affecting health-seeking behavior related to common cancers and their various aspects among the rural population.

Materials and Methods

A community-based mixed-methods study was conducted in rural Jodhpur, Rajasthan. Jodhpur district consists of 65.7% rural and 34.3% urban population. The total rural population of Jodhpur district comprises 24,22,551 (M:12,60,328 and F:11,62,223) persons. Administratively rural areas of Jodhpur are divided into ten blocks [10]. The Mandore block was selected by simple random sampling from the sampling frame of ten blocks. The rural area of Mandore block consists of 1,89,931 persons (M: 95,538 and F:91,393) [10]. There were 113 villages in the selected block, out of which 1/3rd of the total number of villages (37 villages) were included in the study. Data was collected from individuals diagnosed with cancer and their relatives. Contacts with study participants were established with the help of ANMs/ASHAs/Anganwadi workers and local leaders.

The study participants were contacted after liaising with healthcare workers (AWW, ASHA, ANM) and community leaders (formal and informal leaders) to identify cancer cases and deaths due to cancers in the study area. Caregivers with a diagnosed case of cancer or death due to cancer in the last 15 years in selected villages were also contacted to collect information. Written informed consent was taken from participants. Strict confidentiality was maintained.

An interview-based questionnaire was used, which consisted of questions about the year of diagnosis, place of diagnosis, treatment hospital, type of hospital, use of alternative medicine, continuation of treatment, difficulties faced during treatment, and follow-up after treatment.

Statistical Analysis

The data were entered in Microsoft Excel 2011, checked for errors, and cleaned before analysis. Categorical variables were reported as frequency and percentage, while continuous variables were reported as median and interquartile range (IQR). Statistical analysis was done using STATA version 16 (StataCorp, 2019). Statistical Software: Release 16. College Station, TX: StataCorp LLC).

The interview guide (attached as Annexures) for In-Depth Interviews (IDI) included 10-11 questions to explore awareness and perception and identify factors that influence the health-seeking behaviour of cancer survivors. Prior permission was sought before interviewing each participant. Each interview lasted for 25-30 minutes. All interviews were conducted by the primary investigator, who was trained in both the theoretical foundations and the application of relevant qualitative techniques. The tools were developed in English and translated into “Hindi” the local language, using a back-translation process as quality assurance for participants who were not fluent in English.

Voice-recorded information was first transcribed into verbatim without dialect by the researcher (which included both English and Hindi) and later translated into English. Meaningful data were freely coded. Categories were reduced to major themes through ongoing discussion and the rereading of transcripts by the coders. Translated information was coded based on the research objective. The codes were grouped into sub-themes and finally into main themes. The coding, and grouping into sub-themes and themes were done by two researchers with experience in qualitative research. The results were finally presented on the overall themes as narratives and supported with quotes.

GIS was used to depict healthcare facilities accessed by cancer patients. Geo-coordinates of every healthcare facility were identified, and the households were recorded using Google Maps. For mapping data of all patients and health care facilities were maintained on the spreadsheet created by using MS Excel 2011. Geocoded data were added to it by transferring geo coordinates from the device. Subsequently, they were checked and duly corrected before analysis. Maps were generated using QGIS for Desktop v3.

Results

The present study included 37 villages covering a population of 82983 persons (M:42928 and F:40055). Among the total population, there were 146 diagnosed cases of cancer (Figure 1). Out of the 146 study participants, 88 (60.3%) were males. The ages of the study participants ranged from 6 to 84 years. The majority of the participants (63, 43.2%) were in the age group of 60-79 years. Most of the cancer patients were Hindu by religion (93.2%, 136). Among 146 cancer patients, more than 40% (45.2%, 66) patients were alive. Almost 44% (64) of the participants were unemployed which included homemakers - 34.9% (51) and students - 3.4% (5). 42.5% (62) of participants were illiterate while only 4.2% (6) of them were professionals. One-fourth (26.7%, 39) of participants belonged to the upper-middle class while 26.0% (38) belonged to the lower-middle class (Table 1).

Among the 139 participants (7 participants were not taking any treatment), 67% (98) of cases took treatment from the Jodhpur district. Most (79%,110) of the participants took treatment from government hospitals, which included both tertiary centres and cancer

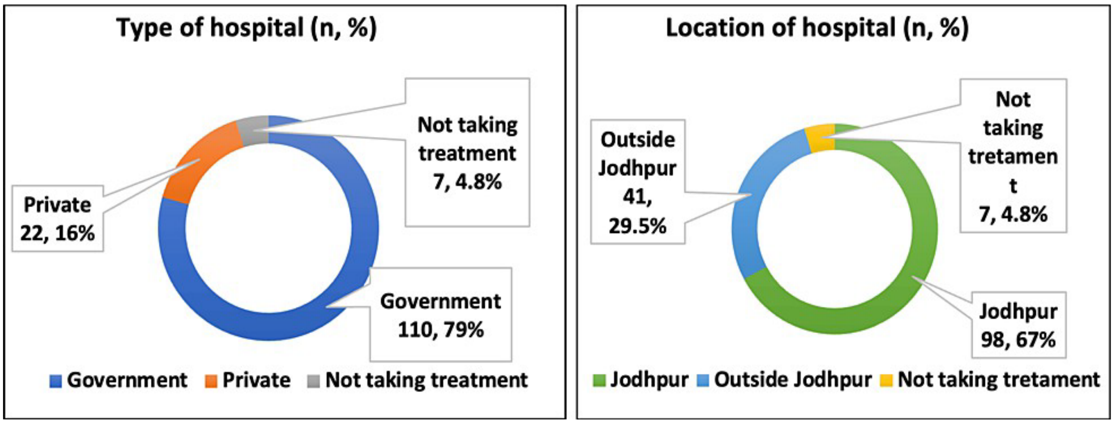

Figure 1. Type and Location of Hospitals Utilised by Cancer Patients

Table 1. Distribution of the Study Participants based on Their Sociodemographic Characteristics (N = 146)

Variable	Frequency (n)	Percentage (%)
Age (years)		
<10	2	1.4
10-19	3	2
20-39	17	11.6
40-59	56	38.4
60-79	63	43.2
>80	5	3.4
Gender		
Male	88	60.3
Female	58	39.7
Religion		
Hindu	136	93.2
Muslim	10	6.8
Type of family		
Joint	78	53.4
Nuclear	68	46.6
Occupation		
Professional	17	11.6
Semi profession	9	6.2
Clerical/Shop/farm	33	22.6
Skilled worker	6	4.1
Semiskilled worker	2	1.4
Unskilled worker	15	10.3
Unemployed*	64	43.8
[*Unemployed – 5.5% (8) Home maker – 34.9% (51) Student – 3.4% (5)]		
Education		
No formal education	62	42.5
Primary school	13	8.9
Middle school	16	10.9
High school	10	6.8
Intermediate/Diploma	24	16.4
Graduate	15	10.3
Professional	6	4.2

care centres. (Figure 2) Among all the participants, 7 (4.8%) cases did not continue their treatment after being diagnosed with cancer. Two among them were suffering from gastrointestinal cancer, and three had oral cancer, one from a primary brain tumour and one from leukaemia. More than one-third (20, 36.4%) of participants with head and neck cancer and more than one-fourth (26.3%, 5) of participants with breast cancer took both allopathic and complementary medicine (Table 2).

Excluding the participants who did not continue their treatment, a follow-up pattern was studied, and it was classified as a regular follow-up (monthly/2-monthly/3-monthly), irregular follow-up (as and when required), and lost to follow-up. Irregular follow-up was highest among people suffering from a primary brain tumour (2, 25%), followed by gastrointestinal cancer (5, 22.7%), and breast cancer (2, 20.5%) (Table 3) There was a clustering of cancer cases in and around the location of health facilities of all levels (primary, secondary, tertiary, and cancer care centres), as shown in Figure 2. More than half of the patients suffering from primary brain tumour (5, 62.5%), head and neck cancer (32, 56.4%), and breast cancer (10, 52.6%) changed their hospitals frequently (Table 4).

Qualitative Analysis

Based on In-Depth Interviews conducted with frontline workers, cancer survivors, and cancer caregivers, the following themes were developed. Qualitative analysis of In-Depth Interviews is explained under the headings verbatim, codes, sub-themes, and themes. IDIs with ASHA/ANM/Community leaders are described in Table 5. All the participants were females with work experience of more than 10 years. Interviews were conducted till data saturation was reached. A total of five interviews were conducted. In Table 6, IDIs with cancer survivors are explained. Two cancer patients were selected from six major types of cancer (Head and neck cancer, gastrointestinal cancer, Breast cancer, Soft tissue sarcomas & Bone cancers, Gynaecological malignancies and Primary Bone tumours). A total of 9 interviews were conducted till data saturation was reached. In Table 7, IDIs with cancer caregivers are explained. They were also selected in the same pattern as the cancer survivors. A total of eight interviews were conducted till the data

Table 2. Different Modes of Treatment among Cancer Patients

Type of Cancer	Types of treatment		No treatment
	Only allopathic	Both allopathic and alternative medicine	
Head and neck cancer* (55)	32 (58.2%)	20 (36.4%)	3 (5.5%)
Breast Cancer (19)	14 (73.7%)	5 (26.3%)	0 (0%)
Gastrointestinal Cancer** (22)	11 (50%)	9 (41%)	2 (13.3%)
Other Cancers*** (50)	32, (64%)	16 (32%)	2 (4%)
Total (146)	92 (63%)	50 (34.2%)	7(4.8%)

*Head and neck cancer; Oral cancer, Laryngeal Cancer, Nasopharyngeal Cancer; **Gastrointestinal Cancer; Tumors of UGI (Esophageal Cancer, Stomach Cancer, Small intestine cancer), Tumors of LGI (Colorectal cancer, Tumors of Appendix); ***Others – Soft tissues and Bone Carcinoma, Gynecological Malignancies, Primary brain tumors, Tumors of liver and biliary tree, Bladder and Renal cell carcinoma, Lung Cancer, Skin Cancer, Testicular Cancer, Endocrine Malignancies, Prostatic Cancer

saturation was reached.

Theme 1: Limited awareness

Under this theme, Sub-themes included were a) general awareness about cancer b) warning signs about cancer c) awareness about screening/preventive measures. These factors were one of the important determinants of delayed health-seeking behaviour. Almost all the interviewees were aware of the harmful effects of smoking or chewing tobacco products, which could be explored to bring about favourable behaviour, but most of them did not know any other risk factors. They had limited awareness regarding the warning signs of cancer. Cancer survivors were aware of the symptoms that they went through, like ulcers in their mouths. Irregular mass and vaginal bleeding were other answers to the question regarding warning signs of cancer. None of the participants were aware of existing screening services, even the frontline workers were unaware of it.

Theme 2: Factors for health-seeking behaviour

Delay in health-seeking behaviour among cancer patients is multifactorial. Various factors can be divided into two levels – individual level and at the health system level. Existing misconceptions regarding treatment modalities, side effects of treatment, lack of family support, stigmatization, and discrimination from society were the major factors that affect an individual's decision. Whereas lack of a proper referral system, misdiagnosis or delay in diagnosis, high cost of treatment and diagnosis in private hospitals, other preferred modes of treatment like ayurvedic, homoeopathic, etc., shuffling between different treatment centres were the main contributing factors.

Theme 3: Recommendations to improve cancer prevention and control

On analyzing the interviews given by frontline workers, the recommendations given by them were to establish a dedicated peripheral centre for cancer patients, availability of initial treatment at peripheral centres, guidance for referral, modes (radiotherapy, chemotherapy, and surgery), and cost of treatment. For increasing awareness regarding cancer among common people and even among healthcare workers, training, rallies, skits, etc., were recommended. To prevent stress among cancer survivors, the appointment of a counsellor at the peripheral centre was also recommended.

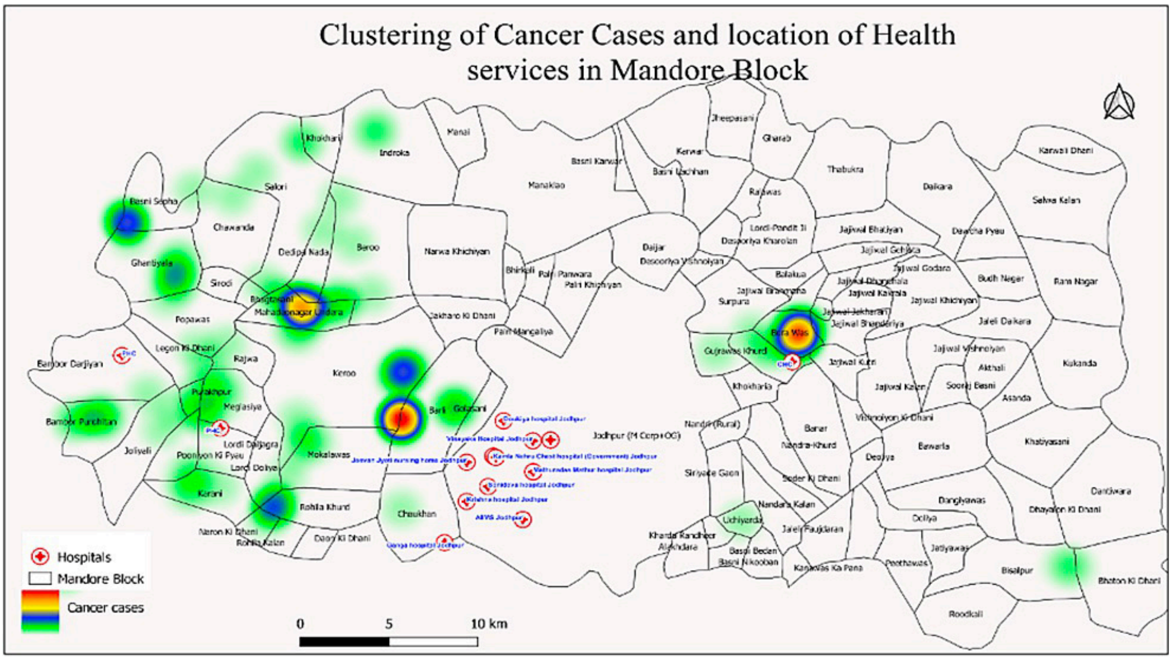

Figure 2. Location of Health Centres Availed by Cancer Patients

Table 4. Frequency of Change of Hospitals among Cancer Patients

Type of Cancer		Total	Change in hospitals		Frequency of Change of hospitals		
			Yes	No	More than once (n, %)	More than twice (n, %)	More than thrice (n, %)
Head and Neck Cancer		55	32 (56.4%)	23 (43.6%)	28 (90.3%)	3 (9.7%)	1 (3.1%)
Gastrointestinal Cancer		22	10 (45.5%)	12 (54.5%)	9 (90%)	1(10%)	0 (0%)
Breast Cancer		19	10 (52.6%)	9 (47.4%)	8 (80%)	1 (10%)	1 (10%)
Other Cancers (50)	Soft tissue sarcomas and Bone cancers	14	5 (35.7%)	9 (64.3%)	3 (60%)	1 (20%)	1 (20%)
	Gynecological Malignancies	9	2 (22.2%)	7 (77.8%)	1(50%)	1(50%)	0 (0%)
	Primary Brain tumours	8	5 (62.5%)	3 (37.5%)	2 (40%)	2 (40%)	1(10%)
	Remaining Cancers*	19	14 (73.7%)	5 (26.3%)	12 (85.7%)	2 (14.3%)	0 (0%)
Total		146	78 (53.4%)	68 (46.6%)	63 (80.8%)	11 (14.1%)	4 (5.1%)

*Tumours of liver and biliary tree, bladder and renal cell carcinoma, lung cancer, skin cancer, testicular carcinoma, endocrine malignancies, prostatic cancer

Table 3. Type of Hospital, Place of Seeking Treatment and Follow-up Pattern among Cancer Patients

Type of Cancer		Currently Seeking Treatment# (n=139)		Place of Treatment# (n=139)		Regular follow up	Irregular follow up	Lost to follow up
		Government n (%)	Private n (%)	Jodhpur n (%)	Outside Jodhpur n (%)	(n, %)	(n, %)	(n, %)
Head and Neck Cancer (55)		43 (78.2%)	9 (16.4%)	38 (69.1%)	14 (25.5%)	31 (56.4%)	7 (12.7%)	17(30.9%)
Gastrointestinal Cancer (22)		17 (77.3%)	3 (13.6%)	15 (68.2%)	5 (22.7%)	14(63.6%)	5 (22.7%)	3 (13.7%)
Breast Cancer (19)		16 (84.2%)	3 (15.8%)	13 (68.4%)	6 (31.6%)	16 (84,2%)	2 (20.5%)	1 (5.3%)
Other Cancers (50)	Soft tissue sarcomas and Bone cancers (14)	10 (71.4%)	3 (21.4%)	11 (78.6%)	2 (14.3%)	6 (42.8%)	2 (14.3%)	6 (42.8%)
	Gynecological Malignancies (9)	9 (100%)	0 (0%)	8 (88.9%)	1 (11.1%)	7 (77.8%)	0 (0%)	2 (22.2%)
	Primary Brain tumours (8)	4 (50%)	3 (37.5%)	1 (12.5%)	6 (75%)	5 (62.5%)	2 (25%)	1(12.5%)
	Remaining Cancers * (19)	17 (89.4%)	2 (10.5%)	12 (63.1%)	7 (36.8%)	15 (78.9%)	3 (15.8%)	1(5.3%)
Total		116 (83.4%)	23 (16.5%)	98 (70.5%)	41 (29.5%)	94 (64.4%)	21 (14.4%)	31(21.2%)

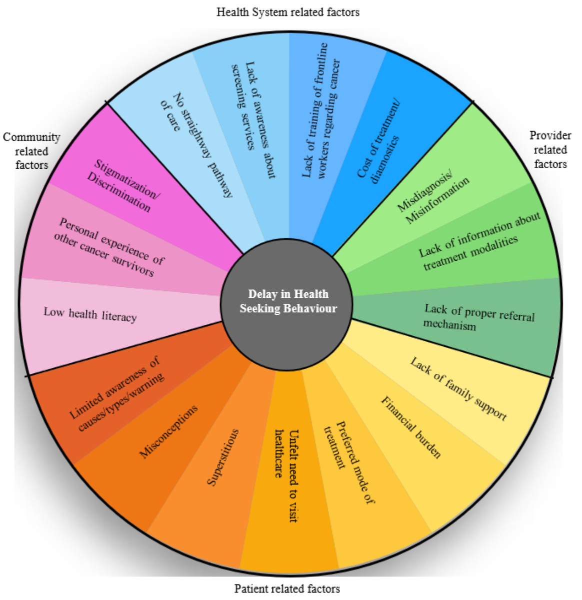

Figure 3. Conceptual Framework Showing Factors Affecting Health-Seeking Behavior

Conceptual framework

All the analysed factors were divided into four categories: patient-related, doctor/provider-related, community-related, and health system-related factors. A conceptual framework was prepared indicating how these factors contribute to a delay in health-seeking behaviour. (Figure 3).

Discussion

In the current study, 34.2% of cancer patients were using alternative medicine along with allopathic medicine. A global study conducted by Akhter et al. [10] reported a higher prevalence of alternative medicine use (55.0% in Asia and 56.6% in India) among cancer patients, which was more as compared to the current study. The results of the study conducted by Broom A et al. [11] reported that 34.3% of cancer patients used complementary and alternative medicine. Another study done by Kumar D et al. [12] also reported similar findings, in which overall complementary alternative medicine use was found to be 38.7%.

In the current study, during the whole course of treatment, 79% of the cases used treatment and diagnostic facilities of government hospitals, while 16% of the cases went to private healthcare centres. According to the study conducted by Ngangbam S and Roy [13], utilisation of healthcare facilities among the rural population in government facilities was 82.5% (primary health services - 53.3% and public hospitals - 29.2%), whereas in private hospitals, it was 17.6%. The study done by Nair S K et al.

Table 5. Qualitative Analysis of In-Depth Interviews of ASHA/ANM/community Leaders

Verbatim	Codes	Sub-themes	Themes
"I have not heard any cancer due to alcohol intake" "People should eat more fruits and vegetables for the prevention of cancer"	General awareness of Cancer/ Types of Cancer Warning signs of Cancer	Cause of certain cancer not known	Limited awareness
"Cancer can be cured by itself" "Cancer patients will die" "Cancer is dangerous and there is no treatment for cancer"	Misconceptions	Individual-level	Factors for delayed health-seeking behavior
"People in the village first go to any temple or pray to God [Devta Bhaithana] and think that God will take away this curse and they will be cured" "If they don't pray for one day or don't give coconut water to God, they will suffer from cancer"	Superstitions		
"Sitting, eating and living with cancer patients is the cause of cancers in others"	Stigmatization/ Discrimination		
"Cancer will be cured by itself"	Unfelt need to visit the healthcare		
"Most of them preferred going to some local healer [Neem Hakim/Jhaad Phuk] and when size increases, they go to hospitals"	Preferred mode of treatment		
"Instead of Jodhpur, they prefer going to Ahmedabad and Bikaner"	Pathway of care	Health system level	
"In the first visit, no doctor tells what it is, the patient has to visit frequently before the final diagnosis is made"	Miscommunication / Lack of information from the doctor		
"First most of the villagers don't have money, even if they have, they have no idea what treatment should be taken"	Treatment modalities/ Financial burden/ Cost of treatment		
"Even we ANMs/ASHAs don't know much about screening services, how common people will know"	Government programmes / Screening services		
"At least the primary or initial level of treatment should be available in villages"	Establishing peripheral health facilities dedicated to cancer / Availability of initial treatment at peripheral centers Availability of counselor at peripheral centers for referral and guidance	Recommendations for health care facilities	Recommendations to improve cancer prevention and control
"Going house to house will not generate interest and awareness as these gathering will do"	Roleplay, skit, IEC activities, rallies for awareness	Recommendations for IEC/training activities	
"School teachers can spread awareness through students and parents who attend parents' teacher meeting"	Training activities – teachers, ANM, ASHA		

Table 6. Qualitative Analysis of In-Depth Interviews of Cancer Survivors

Verbatim	Coding	Subthemes	Themes
"Tobacco, beedi, cigarette" "I heard insecticide sprayed in fields causes cancer"	Limited awareness/ Misconceptions about the causes of cancer	Causes/Type of cancer/ Warning signs of cancer	Limited awareness
"Any irregular mass, bleeding" "Ulcer on the tongue and in the mouth"	Less knowledge of warning signs/symptoms		
"I don't know anything, about it"	Screening services/prevention	Screening services	
"They said I will die if I get operated" "Just eat fruit, vegetables, and milk you will be okay" "Cancer can also be treated without medicine	Misconceptions	Individual-level	Factors affecting health-seeking behavior
"My family members kept my children away, they said cancer spreads to other people" "If I talk or live with them, they might get cancer"	Discrimination/ Lack of family support		
"It took almost six months treatment from Jodhpur before going to Ahmedabad"	Lack of referrals services	Health system level	
"I went to 2-3 doctors before my treatment was started"	Pathway to care		
"I took Ayurvedic medicine, but the swelling did not decrease" "People in my village go to Bhilwara for taking ayurvedic medicine"	Treatment from Indigenous systems of medicine		
"Travelling to Ahmedabad used to cost 7000-8000 Rs per month"	Private facilities and cost of treatment/ diagnostics, Distance/travel-related		
"There was a gap of almost one year before proper treatment started"	Delay in treatment		
"We have Bhamashah Card that helped in Jodhpur"	Utilization of Social security scheme		
"Sometimes there is swelling in the neck and I have difficulty in eating"	Associated complaints		Post cancer hardships
"During treatment, I was staying alone in Jodhpur, there was constant loneliness"	Stress		
"There is fear in the community regarding the treatment of cancer and regarding radiotherapy, most of the people die after radiotherapy	Misconceptions regarding side effects of treatment		

[14] in Kerala reported that about 45% of cancer patients used private health facilities as the first point of contact for cancer-related diseases, as against 32% in public hospitals. This difference could be due to the lack of involvement of the primary health system in cancer control activities, particularly in rural areas. In the current study, more than half of the cancer patients (53.4%) changed their healthcare provider. Similar results were reported by Hewitt M et al. [15], as most cancer survivors (55.7%) had obtained a second opinion or multiple opinions regarding their treatment. In a study by Mellink W A M et al. [16], 62% of cancer patients opted for a second opinion which is slightly higher than the present study. The study done by Swaminathan R et al. [17] showed that 26% of cases who were lost to follow-up after five years from diagnosis were suffering from lip cancer, which was comparable with the results of the present study, where 30.9% of head and neck cancer cases were lost to follow up. Paul Misu et al. [18] conducted a study on cervical cancer patients registered in the regional cancer centre, in Kerala. They reported that among 690 cases who had completed the initially planned treatment, 34% were lost to follow-up.

Table 7. Qualitative Analysis of In-Depth Interviews of Cancer Caregivers

Verbatim	Coding	Subthemes	Themes
"I only know about tobacco, alcohol, and beedi"	Causes of cancer		Limited awareness
"My uncle was unable to eat and his ulcer increased in size"	Warning signs/abnormal signs of cancer		
"I have not heard about these tests"	Screening services/Preventive services		
"I have Bhamashah card, treatment cost was less in Bikaner"	Utilization of social security schemes	Individual related	Factors affecting health-seeking behavior
"First we went to a private clinic from there to MDM hospital because ulcer increased in size and he was unable to eat.	Inciting factors – disease symptoms/manifestations causing disability		
"All his friends and family believe that cancer is an untreatable disease	Personal life experience of others affecting HSB	Health system-related	
"Treatment was possible because I live in Jodhpur but in the villages, there are no services for cancer treatment"	Pathway to care		
"Private centre – MDM- AIIMS – Cancer centre Bikaner"	Shuffling between centres		

Based on the content analysis, we found that health-seeking behaviour was a multifactorial phenomenon and numerous factors at multiple levels contribute to a delay in health-seeking behaviour. Patient-related factors included limited awareness of causes/types/ warning signs of cancer, misconceptions, superstitions, unfelt need to visit healthcare, the preferred mode of treatment, financial burden, and lack of family support. Kumar A. et al. [19] reported similar findings for reasons of delay, such as misconceptions about the disease, perceived stigma, fear and denial of the presence of cancer, and family responsibilities. Kumar A et al. [19] also reported barriers to treatment delay from the provider's side, which include misclassification of disease severity, poor accessibility and affordability, fear of treatment, and its side effects. Similar reasons were quoted by participants in our study, which were grouped as the provider or doctor-related factors Lack of awareness, financial constraints, and lack of perception of seriousness were the main barriers from the patient's point of view, as reported in a study done by Rath H et al. [20]. Knowledge deficits regarding early diagnosis, economic barriers to accessing care, and fear about diseases were the main barriers to accessing health care, as reported by the study done by Sharp et al. [21] There was poor awareness regarding cancer screening, its benefits, and its uses among participants. Most of the studies done in India showed better results regarding awareness about cancer than the current study. This can be attributed to the low level of literacy among the participants in the current study, as it was conducted in rural populations. Most of the participants of the present study stated that cancer was a contagious disease. As a result of which, discriminating behaviour towards cancer patients was prevalent in the community. Cancer patients were separated from society, and the attitude of society towards cancer patients was not positive, which clearly shows a lack of awareness regarding cancer and its causes. In a study done by Thilak GP [22] in rural Karnataka, 34.6% of participants were scared by seeing cancer patients. As reported by the study done by Binka et al. [23], institutional-level barriers are perceived health personnel attitude, perceived lack of privacy, and misdiagnosis. In the study done by Robb et al. [24] in Britain, apart from service barriers (such as difficulty in talking to the doctor, worried what the doctor might find, being too scared of the condition, and not being confident to talk about symptoms), there were few practical barriers also such as too busy in work and difficult to arrange transport.

Limitations

Due to prevalent stigmatization and discrimination with cancer survivors, few cases did not give consent. Responses of females could be affected by the presence of other family members. As the patients or primary caregiver had to recollect information over a long period of time, for the questions posed, the chances of recall bias in the present study cannot be overlooked.

In conclusion, the awareness of risk factors was mostly limited to tobacco and alcohol. Less knowledge regarding the causes of cancer and prevalent superstitious beliefs regarding its treatment prevented the general population from seeking health care. None of the study participants were aware of the screening services provided and the benefits of screening services. The financial barrier was the most common factor for delay in seeking healthcare. General awareness regarding screening services was limited among front-line workers also. Public health facilities were the preferred mode of treatment by most of the participants. Further

interventions should include not only behavioural changes at the individual level but also focus on health system strengthening through vigorous training and awareness sessions.

Author Contribution Statement

PR, GS and NR conceived and designed the study; GS acquired data; GS and PR analysed and interpreted data; GS drafted the initial manuscript. PR, NR and GS performed critical revisions of the manuscript and finalized the manuscript. All the authors approved the final version of the manuscript.

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The present study was a part of the approved student thesis and it was approved by the Institute's Ethics Committee.

Ethical Approval

Ethical permission for the present study was taken from the Institute's Ethics Committee, AIIMS, Jodhpur, Rajasthan, India, vide letter no. AIIMS/IEC/2018/576 dated 24/12/2018.

Availability of data

Deidentified patient data will be made available with corresponding author's permission, with a signed data access agreement

Conflict of interest

None.

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